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ABSTRACT

This consensus report on supported employment for people with severe mental retardation was a product of a conference which brought together the expertise of consumers, practitioners, researchers, family members, and analysts. Determinants of success in supported employment for this population are identified along with critical issues for implementation, and research questions for the future. Principles agreed upon include the following: focus on supports, not labels; emphasis on the choices of the affected individuals, their families, and friends; individualized job matches; expanded involvement of people with severe mental retardation; and organizational commitment to improving choice and integration. Six specific issues are addressed: (1) the personal and functional characteristics of people with severe mental retardation who are presently included in supported employment; (2) the individualized practices and strategies currently used in successful supported employment outcomes; (3) the employer-developed strategies and practices which support successful outcomes; (4) the organizational structures and strategies which support successful implementation of supported employment; (5) the local community structures and policies (local, state, and federal) which support successful implementation; and (6) needed future research. (DB)

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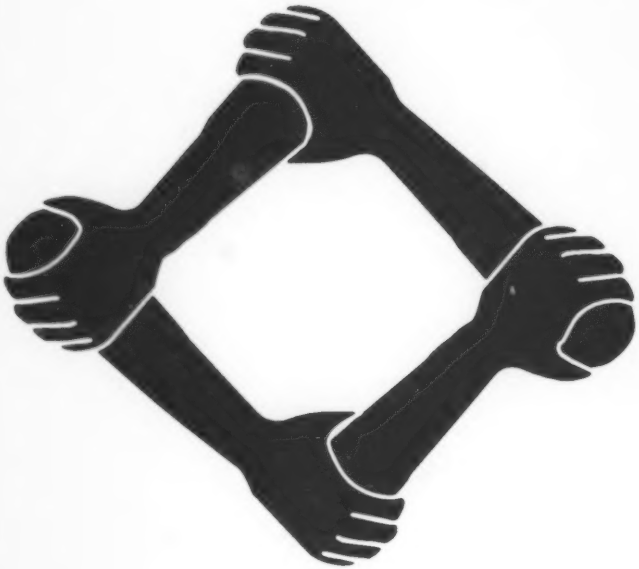

Supported Employment for People with Severe Mental Retardation

CONSENSUS STATEMENT

National Institute on Disability and Rehabilitation Research
May 23-26, 1993

Volume 1, Number 5

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The National Institute on Disability and Rehabilitation Research (NIDRR) Consensus Validation Conferences are convened to evaluate and synthesize available scientific information and to improve the dissemination of findings from rehabilitation research. It is anticipated that practices discussed in this statement will be adopted by practitioners and consumers.

NIDRR Consensus Statements are prepared by a nonfederal 10-member panel, based on (1) resource papers prepared by experts; (2) testimony presented by researchers, clinicians, and consumers during a one-day public hearing; and (3) a day of closed deliberations by the panel during which the consensus statements are prepared. This statement is an independent report of the panel and is not a policy statement of NIDRR or the federal government.

Copies of this statement are available from:

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Abstract

Supported employment evolved from a small number of demonstration projects in the early 1980s to a major national thrust that has created unprecedented employment opportunities for people previously perceived as too severely disabled to engage in meaningful work. Supported employment, originally defined as paid work in integrated settings with ongoing support for as long as needed, quickly moved from concept to regulation with stringent guidelines that defined minimum criteria for both integrated and follow-up support.

One recent national study reported over 74,000 individuals receiving supported employment from over 2,600 provider agencies in 1990. That number has increased significantly since then. With this growth has come the evolution of supported employment "models," such as individual placement, mobile crews, and enclaves, all of which typically include the involvement of a job coach or similar professional to train and support employees with disabilities in integrated work settings. Recent initiatives have been developed that look toward the employers and the "natural" support of the work environment to augment or replace the intervention of supported employment professionals.

Supported employed has been successful in getting people to work, but there are criticisms that more effort should be directed toward more severely disabled people. Data from a 1990 survey show that people with mild mental retardation have been the primary recipients of supported employment services, with only 12.2% of those served being persons with severe mental retardation.

This Consensus Conference brought together the combined expertise of consumers, practitioners, researchers, family members and analysts in an effort to arrive at consensus on the present status of, and the best practices in, supported employment for people with severe mental retardation.

This Consensus Statement represents consensus about important determinants of success in supported employment of people with severe mental retardation. It discusses critical issues for implementation and research questions for the future. Several overriding issues about supported employment for people with severe mental retardation were validated through the consensus validation process and are discussed in this document.

Introduction

People with severe mental retardation are capable of performing valued, meaningful work. The task of supported employment is to provide them with both the opportunity and the supports they need to work.

The supported employment initiative began in the early 1980s with an emphasis on people with the most severe disabilities and a particular focus on people with severe mental retardation. Individuals and their advocates have long been dissatisfied with the employment and integration outcomes of developmental and activity programs and sheltered workshops. Since supported employment was first defined in 1984, more than 75,000 individuals have gained access to employment with long- term supports. A small percentage are labeled severely mentally retarded. There is mounting concern that the growing popularity of supported employment for people who need less complicated supports will result in excluding people with severe mental retardation.

The issue is not whether other individuals in supported employment need jobs or need support to be successful. The issue is about the pace of program implementation and the inclusion of people with severe mental retardation in supported employment. Despite the fact that supported employment was begun in response to employment needs of people with severe mental retardation, there is concern that they are underrepresented in the ranks of those in supported employment.

This document represents consensus about important determinants of success in supported employment of people with severe mental retardation. It discusses critical issues for implementation and research questions for the future. Several overriding issues about supported employment for people with severe mental retardation were validated through the consensus validation process.

Focus on Supports Not Labels

Severe mental retardation is a label that defines eligibility for services rather than potential for working and contributing in society. While the assigned task for the consensus panel was specific to supported employment for people with severe mental retardation,

many of these issues and solutions reflect the needs and hopes of others with different but equally challenging disability labels.

Investment in Choice

Supported employment and rehabilitation should increasingly implement the choices of people with disabilities, their families, and friends. For people with severe mental retardation, this means creating options that reflect meaningful choices and improving their communication and decision-making skills so they can better understand those choices and preferences.

Individualized Job Matches

The most successful examples of supported employment can be characterized as having an individual well matched to a specific job and in a typical employer-employee relationship. While group placements such as enclaves and other such working arrangements meet minimum regulatory definitions of supported employment, individualized jobs are likely to be more integrated, higher paid, and less expensive in the long term to the public funder.

Expanded Involvement of People With Severe Mental Retardation

Involvement of people with severe mental retardation in decision-making processes is a complex issue. The planning and conduct of this forum would have benefited from greater participation of people with severe mental retardation and their families. Other discussions of disabilities will benefit from the participation of people with severe mental retardation.

Organizational Commitment to Improving Choice and Integration

The employment of people with severe mental retardation is developed and supported by organizations with vastly different missions and structures. Supported employment is provided by organizations that only provide supported employment—organizations that provided primarily segregated services in the past

but are now committed to a total change supporting integrated employment, and organizations that provide supported employment as one of various employment options. Supported employment is provided most successfully by organizations committed to improving community integration, employment outcomes, and informed choice by individuals with disabilities. These values, buttressed by systematic support and incentives, guide the most successful organizations' purposes, services, and structures.

The Consensus Validation Conference included in a review and discussion of the knowledge and experience of advocates and family members of people with severe mental retardation, providers and funders of services, employers, researchers, and concerned others. Six questions were addressed by the conference and are discussed in these documents. These six questions are:

1. What are the personal and functional characteristics of people with severe mental retardation who are presently included in supported employment?

2. What individualized practices and strategies currently result in successful supported employment outcomes for people with severe mental retardation?

3. What employer development strategies and employer practices promote successful supported employment outcomes?

4. What organizational structures and strategies support successful implementation of supported employment (e.g., human resource development, fiscal resources, new management approaches)?

5. What local community structures promote successful implementation of supported employment programs? What local, state, and federal policies promote successful implementation of supported employment programs?

6. What future research is needed for expanding and improving supported employment for people with severe mental retardation?

1. What are the personal and functional characteristics of people with severe mental retardation who are presently included in supported employment?

People with severe mental retardation and with severe mental retardation in combination with other disabilities can obtain successful integrated employment if they are provided with individualized supports. People with severe mental retardation who are in supported employment experience a much better quality of life than they experienced in the past in sheltered work or day activities programs.

Characteristics of Individuals

People with severe mental retardation in supported employment have a significantly higher incidence of secondary disabilities (as many as half of these individuals have secondary disabilities) and significantly lower functional skills than others in supported employment. They have fewer job-related skills than others in supported employment. Those who experience serious behavior challenges, severe physical disabilities, autism, and health-related problems, along with severe mental retardation, are now included in supported employment.

Employment Outcomes

People with severe mental retardation who are in supported employment realize positive and significant personal, employment, and integration outcomes. They experience greater self-determination in employment and community participation. While these outcomes need improvement in terms of income, benefit, and inclusion, they are far superior to those associated with the past segregation of these individuals.

- Fewer than 9 percent have had community jobs in the past.
- About half have earned some money by working in the past but almost exclusively in segregated employment.
- The average annual wage prior to supported employment was about $557.

- People with severe mental retardation in supported employment work an average of 22 hours a week and earn about $3.50 an hour.

- Nearly 75 percent experience significant interaction with co-workers on the job.

- Approximately one-third receive some kind of company sick leave, vacation, or other benefits.

- Persons employed through the individual placement model earn significantly more money and benefits and experience more integration than people in group placements, such as enclaves or mobile work crews.

Characteristics of Individual Support

In addition to the previously described demographic and outcome characteristics, the following statements describe the support systems and interventions that contribute to successful employment outcomes:

- Successful supported employment occurs within a support system that extends beyond the workplace. People with support systems that enable full participation in community life are more likely to have opportunities to join the work force and become successfully employed.

- Success in the workplace and full participation in community life are dependent upon "intentional strategies" — planned instruction and systematic feedback to the individual. Basic work-related behaviors (such as following multistep directions or initiating appropriate social interactions) are present to a significantly lesser degree in people with severe mental retardation than in people who have mild or moderate retardation. Planned instruction and direct service interventions are needed and effective for people with severe mental retardation.

- Successful employees with severe mental retardation benefit from individualized planning processes. Strategies are developed through ongoing individualized planning

that uses the full, consumer-driven involvement of all participants and is not directed by human service professionals. Because so few people who are labeled severely mentally retarded and who are in supported employment have experienced previous community employment, special attention is required in job selection and determination of probable support systems.

- Long-term involvement of family or other personal advocates with clear vision and commitment ensures continuity in services and long-term supports. People with severe mental retardation who are successful in the workplace depend on parents or other family members or involved advocates to ensure that their choices and support needs are realized in employment and community settings.

- Belief that people with severe mental retardation can be fully integrated into employment is more important than any specific skills for implementation. If support personnel believe that people with severe mental retardation should work and believe they are capable of performing valued work, then the staff skills for training and support can be learned.

2. What individualized practices and strategies currently result in successful supported employment outcomes for people with severe mental retardation?

A successful system of supported employment begins with a vision that is person-centered, has the person with severe mental retardation as a valued member of the workplace, includes supported living in the community, focuses on inclusion, defines supports rather than services, and is individualized.

Individualized Practices and Strategies

There are six essential ingredients in progressive individualized practices for successful supported employment for people with severe mental retardation, all of which are driven by the commitment that people with severe mental retardation can succeed in supported employment.

Comprehensive planning. Successful supported employees benefit from values-based, comprehensive planning. For students, the school years provide the training ground to plan and assist these future workers to develop essential skills needed throughout their lives. For other adults, the planning may begin with the opportunity for supported employment. The following strategies have been demonstrated to enhance success:

- A comprehensive plan is individualized and addresses the needs of the potential worker, recognizing likes, dislikes, strengths, weaknesses, and personal goals. For students, this is the individual transition plan. For adults the plan takes many different forms, for example, personal futures plan, individualized written rehabilitation plan (IWRP), and so forth.

- This plan utilizes community activities in natural and integrated environments. The plan designates opportunities for people to use skills in integrated settings.

- A comprehensive plan results in students gaining jobs prior to graduation.

- It involves families, other community members, and local businesses.

Choice. Consumer choice drives the planning, implementation, and follow-through processes in successful supported employment. In order to understand and support the choices of individuals with severe mental retardation, several things are important:

- Significant time is spent in getting to know individuals to determine special interests, strengths, functional skills, social skills, and other characteristics essential to successful employment.

- Individuals are assisted in setting and pursuing employment goals commensurate with their interests.

- Individuals are assisted in assessing other life activities to determine if additional components might foster successful employment and community integration.

Family and advocate involvement. Involvement of family or personal advocates or equal partners has proven to be a vital element in the success of employees with severe mental retardation in the work force:

- Family members possess unique information about their sons', daughters', brothers', or sisters' skills, interests, and aptitudes and are equal partners in the planning process.
- Families and advocates articulate those roles and responsibilities they will accept as they relate to outcomes in supported employment.
- Families provide information about their familial and cultural values toward work, success, and outcomes.

Individualized system of supports. By focusing on the abilities of the individual and the identified functions of the job and community participation, a system of supports is designed that addresses the unique circumstances of the supported employee. A wide range of considerations go into this planning:

- Resources are identified and involved in the design of the support system and include family, peers, employers, residential supports, health care and Social Security expertise, recreation and leisure supports, and so forth.
- When a need is identified for assistive technology, plans are made to access and utilize such devices.
- A system of personal supports is specified for individuals who need assistance, such as feeding, toileting, mobility, and so forth. These supports may be provided by co-workers, family members, friends, or personal assistants.
- Successful transportation strategies are designed at an individual level. Transportation is a major need for many people in both rural and urban communities where transit systems are either nonexistent or very complex.

Systemic and individualized training and technical assistance. Successful outcomes are dependent on a system that provides opportunities for ongoing values-based, state-of-the-art training and access to technical assistance. Likewise, the successful supported employee has training that matches the requirements of the job and the needs of the individual.

- Personnel and individuals providing supports to individuals with severe mental retardation make use of ongoing training and technical assistance based on the unique circumstances of individuals with severe mental retardation.

- Best practice strategies and technologies are constantly evolving. Consumers, professionals, families, and others with an interest in supported employment receive continual updates on issues such as natural supports, assistive technology, federal and state policy changes, and so forth.

- Individual supported employees need specific services that often require specific skills training. To address these needs, specialized training and technical assistance are available on an ongoing basis to all professionals, consumers, family members, co-workers, and others involved in the support systems of individuals.

Employer relationships. Strong and positive connections with employers are essential to successful long-term employment of people with severe mental retardation.

- Partnerships are forged and sustained among supported employees, agencies, and employers.

- Supported employee professionals are skilled in job development and marketing.

- Internal employer resources, sometimes referred to as natural supports, are identified and used as much as possible.

3. What employer development strategies and employer practices promote successful supported employment outcomes?

Supported employment represents a major shift away from traditional job preparation models for people with severe mental retardation. Rather than relying on lengthy, and often indefinite preparation processes to get people "ready" for competitive employment, supported employment has demonstrated the validity of training people in the same work environment in which ideally they will be employed. Supported employment, a place/train approach, necessitates a different relationship with employers than has been the case in traditional rehabilitation programs in which employers are approached with the promise of a "qualified, work ready" applicant who simply needs a chance.

Until recently, supported employment has not strayed far from the traditional rehabilitation approach that appeals to the altruism of employers. Marketing appeals to employers who, for the most part, have continued to emphasize the human service aspect of rehabilitation and supported employment. In addition to relatively unsophisticated employer development strategies, job development has often been viewed as a minor and, in many organizations, a relatively nonprestigious adjunct to the rehabilitation process.

Successful supported employment programs for people with severe mental retardation regard employment development as a high-status, high priority effort. These providers have adopted marketing approaches that de-emphasize human service approaches by moving from "cause" marketing, that is, promoting supported employment and employment of people with disabilities as a good cause, to "customer" marketing strategies that emphasize the needs of employers as customers of supported employment.

Recent evaluations of supported employment programs offer valuable insights into employer participation and best practices to encourage employers to consider employing people with severe mental retardation. Successful strategies that have emerged include forming new supported employment/employer partnerships, utilizing sophisticated job development and marketing strategies, accessing internal employer resources, and translating supported employment expertise into effective employee management.

Forging Supported Employment/Employer Partnerships

For employers, work is the successful outcome of effective recruitment, hiring, and human resources management. Because this process requires a substantial investment on the employer's part, the employer expects to gain a return on this investment. By understanding the importance of mutual return on investment, supported employment providers are more likely to be regarded by employers as credible and valued partners.

Successful supported employment/employer partnerships are characterized by the following statements:

- There is mutual interest in the success of each party's enterprise. Supported employment programs that demonstrate sincere interest in and knowledge of the employer's operation have had success attracting employer partners.
- Each party invests in relationships for the long-term. Job placement requires cultivating relationships with employers beyond a single inquiry about available jobs.
- Customer service orientation with frequent and helpful followup is offered to employers by supported employment professionals.
- Features of supported employment are matched to the needs of employers. Features of supported employment, such as job analysis, job matching, training, positive behavior support, and long-term followup, are likely to be regarded as benefits by employers, if translated as meeting particular employers' needs.

Supported employment professionals have more to offer employers than an employee recruitment resource. Supported employment providers offer consultation and advice on job design and task design, which results in greater efficiency by workers without disabilities. Supported employment professionals who share their knowledge with employers and show the links among disability management, work productivity, and employment for people with mental retardation have been successful in maintaining partnerships that lead to job opportunities.

Partnerships with public sector employers and unions can result in significant opportunities for employment for people with severe mental retardation. The characteristics described above have been successfully adapted to meet the unique needs of public sector employers and unions particularly in the areas of maximizing flexibility within civil service job classifications. This is a small area of partnership as compared to the amount of private-sector placement. It reflects the challenge of a longer-term approach to marketing and educating the public sector and unions on the features and benefits of supported employment.

Job Development and Marketing

Effective supported employment providers use a variety of techniques to develop job opportunities for supported employment consumers. These approaches include the following:

- Personal contacts are made with potential employers, including those known to have hired people with mental retardation in the past, employers who are friends and relatives of consumers, and other employers known to staff.

- Phone calls, mail campaigns, and "cold calling" of potential employers are also often used to generate employer prospects but with less effectiveness than when relationships with employers are cultivated over time.

- Marketing and job development efforts that emphasize customer service, rather than altruistic appeals concerning disability, contribute to long-standing mutually beneficial relationships.

- Employer-to-employer networking has proven successful. This includes employers directly contacting other employers and providing testimonials about the value of supported employees. Business Advisory Councils (BACs) represent a variation of employer-to-employer networking in which members of a BAC assist supported employment providers in marketing their services.

- Linkages are created with employers when supported employment personnel become contributing members of business organizations such as Chambers of Commerce.

Job development for people with severe mental retardation is labor intensive. Successful supported employment organizations recognize that the responsibilities associated with job development rest with all staff in the organization.

Administrators through receptionists all have contact with the employer public in one way or another. Successful organizations position everyone in the organization to be part of the marketing effort.

Making Use of Internal Employer Resources

Companies routinely assign both money and human resources to recruiting, training, retraining, and retaining their employees. An increasing number of supported employment programs have tapped into these supports and other generic employer resources such as employee assistance programs, co-worker mentors, co-worker teams, training departments, and trade associations.

As employers become more attentive to work force demographics and the increasingly diverse work force, they are more interested in adapting and restructuring employment procedures to accommodate this diversity. As supported employment programs are attentive to workplace changes and business initiatives, they become more sophisticated in identifying these internal employer resources. They are then able to complement these resources with supported employment practices.

By sharing knowledge with employers in the context of diversity management and human resource investment, supported employment providers have been successful in translating their expertise into effective employee management. Supplementing supervisor training in diversity with disability awareness training, for example, has led to placement opportunities. Studies show that employers' reluctant attitudes about the capabilities of people with disabilities dissipate with such training and with personal experience with workers with all types and degrees of severity of disability.

The Americans With Disabilities Act (ADA)

The ADA represents an emerging instrument for employer development. Since employers often have misperceptions about the ADA, supported employment providers have begun to take the opportunity to provide ADA-related education and technical assistance. Since reasonable accommodation is an important concept addressed, supported employment programs can help identify accommodation tools such as the assistance of a job coach, application of assistive technology, and use of low-tech devices such as picture charts that illustrate a task sequence. Pursued in the context of a customer service orientation and meeting the needs of the employer, these activities strengthen partnerships between supported employment and employers.

4. What organizational structures and strategies support successful implementation of supported employment (e.g., human resource development, fiscal resources, new management approaches)?

Organizational structures and strategies that can support successful implementation of supported employment are diverse. Although a small percentage of free-standing programs exist, most agencies have chosen to add a supported employment component to a facility-based program. No more than 15 percent of facility-based agencies have made the decision to totally reallocate their resources to a community employment design. Regardless of this finding, several themes in the supported employment literature and experience relate to organizational structures and strategies that promote successful supported employment outcomes.

Leadership

An essential element in organizations is the leadership's vision and commitment to supported employment. In planning, training, and redirecting resources, this is critical to success in providing supported employment services to people with severe mental retardation. Leadership promotes creativity and risk taking by helping staff pursue new techniques, methods, and strategies in the support of individuals in community employment.

Mission

In organizations that are successfully supporting the employment of people with severe mental retardation, the mission of the organization reflects the values of supported employment. This mission is outcome-oriented and provides the foundation for setting well-defined goals. These goals provide a framework from which strategies are formulated, implemented, and evaluated.

Values in Supported Employment

Progressive organizations place a high value on community-based, highly paid employment opportunities. Paid employment opportunities are actively developed and supported at all levels of the organization.

These organizations encourage individuals to be active participants in the fabric of the workplace and community. This includes developing relationships with peers, co-workers, and other community members.

Effective organizations have shifted from providing services to facilitating supports. Identifying and utilizing an individual's capacities, strengths, and needs is a necessary component of this shift in order to successfully achieve community presence and participation through employment.

Effective organizations are committed to the long-term process of providing supports and have the stability to do so for an indefinite period of time.

Ongoing Evaluation

Organizations successful in implementing supported employment make use of ongoing evaluation of program effectiveness. Evaluation is fluid, ongoing, data-based, and driven by the values of supported employment. It is also conceptualized as a process that links planning, doing, checking, and acting based on both the primary goals of the organization and the feedback received from its multiple customers. Finally, the ongoing measurement of effectiveness includes both a quantitative and qualitative focus.

Agency tracking. Successful agencies track outcomes. At a minimum, these agencies routinely track the number of individuals who are employed at any given time, other services they are receiving, the wages they are earning, the number of hours they are working, and the integration and satisfaction of the employees with disabilities. As the organization matures, additional information is gathered regarding the length of time it takes to secure a job and the relationship between individual-specific issues and employment success. These data are utilized for ongoing decision making.

Customer feedback. An increasing number of successful organizations actively seek customer feedback. This includes obtaining feedback through surveys, focus groups, and individual interviews. These organizations find that quality of service is defined differently by various customers and that any strategy can and should be modified for a particular individual or type of business.

Implementation of Values

Effective organizations use management structures that emphasize the support of staff who are empowered to make decisions and are well trained. Typically, teams are formed that do relationship building, joint problem solving, and information sharing.

There is creative and flexible use of financial resources within these organizations to support positive outcomes for consumers. These organizations seek diverse resources that allow them to be successful in achieving their mission.

Staff development and training are ongoing and focus on competencies that are relevant to the needs of staff providing supports to customers. Training opportunities focus on developing skills that lead to successful employment outcomes for individuals with severe mental retardation.

Effective agencies seek outside support and mentoring opportunities to enhance their organizational competence. This support is obtained by developing strong networks with training and technical assistance organizations with universities, other successful supported employment programs, and businesses.

Implementation of Best Practice

What is considered to be best practice changes over time. Successful supported employment organizations are proactive and responsive to developing technologies and new ideas. These include organizational and management innovations as well as the direct service innovations.

5. What local community structures promote successful implementation of supported employment programs?

Community structures are the beliefs, values, and norms that reflect a community's ethics and history. Community is, at its simplest, the association of citizens who have a shared memory. Following are the features of these community structures:

- Beliefs, attitudes, and norms of behavior that value the contribution of people with severe mental retardation vary among communities and have a significant impact on successful supported employment.

- Service programs that participate as active partners with local associations and communities are in a position to help redefine community values based on individual and community experience.

- Communities can and do respond with acceptance, support, and resources for people who have severe mental retardation and their families if they are approached and challenged. This sense of shared responsibility for community members occurs at the most local level and results in services being redefined as part of what a community does, not something done to a community or added to it.

These features result in the following:

- Identification of people with severe mental retardation as citizens and community members, contributors to the richness and diversity of the community, and people who need support different in scale and type, but not kind,

from other community members. (Within this context, the label of severe mental retardation becomes meaningless.).

- Safety from harm and security that services will not fail for individuals and their families as community members take on varying levels of responsibility, support, and befriending. (This represents capacity that can be used but may not substitute for a safety net, which has to exist for employment and other life supports when community capacity fails or discriminates against people with severe mental retardation.).

- An agreement among community members that generates reciprocal obligations, needs, and rights, which are expressed, defined, and changed as experience, history, and understanding evolve.

What Local, State, and Federal Policies Promote Successful Implementation of Supported Employment Programs?

The Americans With Disabilities Act and the 1992 Amendments to the Rehabilitation Act reaffirm the national priority of full participation of people with severe mental retardation in supported jobs and supported life.

Governmental policies that support these outcomes would include efficient and effective targeting of resources and maximum flexibility in resource utilization, recognizing that local conditions vary tremendously and that "supported employment" cannot be divorced from "supported life" and that consumers and providers alike need the flexibility to access and target their resources in ways that address individual needs. This includes flexibility among educational, residential, vocational, and other funding streams, recognizing the ever-changing, lifelong nature of support needs.

These governmental policies promote service planning and funding directed to individuals instead of programs. They:

- place resources in the hands of consumers, allowing them to seek and purchase the services of their choice;

- make resources available to consumers as they move from service to service or from provider to provider; and

- foster planning that promotes confidence among family members or advocates and others that they have the power and influence to bring about successful outcomes.

Successful policies minimize risks inherent in any change process and help to allay the fear of risks taken by:

- insuring that Social Security, Medicaid, and other entitlements are not adversely affected when consumers control financial resources;

- insuring a knowledge base and support services, which allow consumers to make informed decisions;

- insuring the dissemination of credible success stories to targeted audiences, especially the families of people with severe mental retardation, so people believe it is possible.

Financial policies can encourage supported employment and discourage segregated services. People with severe mental retardation have been successfully employed at highly variable funding levels throughout the country. Successful organizations have used a variety of financing strategies in order to assure adequate resources. These include:

- flexible funding that offers varied means of assuring payment for effective outcomes and program efficiency;

- creativity on the part of the service provider in reallocating resources or using them more efficiently; and

- finding and using additional community, generic, and natural support resources.

Additional successful policy strategies include:

- establishing financial incentives to encourage the transition from facility-to community-based services that protect providers from financial harm during such transitions, and

- offering incentives for service practitioners and providers to support consumers who control their own services.

That which constitutes movement toward desired outcomes varies from community to community and provider to provider. Effective incentives are tailored to the degree of improvement and the element of risk taken by those communities and providers.

Policymakers who promote systems change exemplify the leadership and management practices that are described under question 4 and are applied at community, local, state, and federal levels. These include visionary and value-based articulation of mission, team decision making, power-sharing partnerships with consumers and other stakeholders, investment in human resources, and continual quality improvement. Helping people change involves:

- sharing leadership, power, and decision making with all partners;
- developing personal beliefs in the possible roles individuals can play;
- providing training and technical assistance to develop skills in systems, organizational, and individual implementation of supported employment; and
- sponsoring mentor relationships between peers, experienced practitioners, and experts at all levels.

The reduction of systemic barriers at the federal level has greatly assisted in eliminating perceived and real barriers to employment. In particular, attention to Social Security work incentives and attention to Medicaid reform have reduced disincentives.

6. What future research is needed for expanding and improving supported employment for people with severe mental retardation?

The review of the research literature and the expert testimony provided to the panel make clear that additional knowledge is needed about how to expand and improve supported employment for people with severe mental retardation. The available research to

date provides clarity that the label of severe mental retardation need not be a barrier to successful community employment. Despite the disability labels, despite the presence of additional disabilities, despite histories of segregation and isolation, people with severe mental retardation work successfully in employment if provided individualized supports. As a result, the question of whether or not meaningful employment is possible for people labeled severely mentally retarded is answered with a clear "yes." The critical research questions of the future are related to how all people with severe mental retardation can work and live in communities.

Following is a summary of issues that require further investigation.

Self-Determination, Satisfaction, and Choice

Research is needed to:

- develop and improve methods to increase the participation of individuals with severe mental retardation in developing employment goals and choosing among options;
- assess the satisfaction of people with severe mental retardation and their families with supported employment;
- determine how people with severe mental retardation can better exercise choice in economic and other domains, such as leadership, and the best ways to support supported employment choices; and
- investigate procedures that promote meaningful career advancement and career choice for people with severe mental retardation.

Support Strategies

Research is needed to:

- investigate the range of support roles of practitioner personnel in supporting individuals with severe mental retardation in employment and other domains of community living;

- examine the emerging roles of co-workers and their potential capacity to support the employment of people with severe mental retardation;

- define features of the notion of natural supports and discuss their use, considering the different needs of consumers, employers, and communities;

- investigate the impact of natural supports on wages, stability, retention, and integration;

- investigate the roles of supported employment personnel in developing the participation of co-workers and company personnel; and

- investigate demonstrations of effective assistive technology, including communication supports, in supporting individuals with severe mental retardation in the workplace.

Employer Roles

Research is needed to:

- study present participation of company personnel in supporting non-disabled employees and people with severe mental retardation inside businesses;

- analyze work force initiatives in diversity, management of disability services, and ADA compliance and their possible impact on supported employment;

- determine the most effective training methods for supported employment practitioners to expand knowledge and skills in "customer" marketing strategies and relationships with employers; and

- explore partnerships with public sector employers.

Organizational Implementation Issues

Research is needed to:

- study the various organizational structures and management practices of organizations that successfully support the employment of persons with severe mental retardation;
- study and describe organizations that have successfully converted from segregated services to supported employment; and
- compare the leadership roles and management skills in three types of supported employment organizations: the stand-alone supported employment agency, the agency converting from segregated to integrated employment, and the agency that offers supported employment as one of a number of options.

Community Development Issues

Research is needed to:

- study methods for increasing the extent of people with severe mental retardation contributing to and being perceived as contributing members of their communities;
- determine methods for increasing the involvement of community members in the lives of people with severe mental retardation;
- identify community development strategies that contribute to the acceptance of people with severe mental retardation; and
- identify supports needed for families to accept the perceived and real risks of supported employment.

Personnel Preparation

Research is needed to:

- conduct studies of the range of personal and educational characteristics of successful supported employment personnel and the outcomes they achieve for individuals with severe mental retardation;
- study the mix of supports provided by company personnel and supported employment personnel and compare the characteristics of each group;
- assess the effectiveness and impact emerging in service training strategies, curriculum, and formats on supported employment;
- analyze the effectiveness of existing and emerging preservice training strategies or supported employment; and
- investigate training relationships between businesses and rehabilitation personnel.

Policy Issues

- conduct an analysis of contradictory policies and contradicting roles and relationships at state and national levels related to integrated employment for people with severe mental retardation;
- analyze funding incentives and disincentives that exist at local, state, and national levels;
- study the local and state policy leadership that is resulting in expanded supported employment for people with severe mental retardation; and
- investigate methods for increasing the control of individuals with disabilities over the resources for supported employment.

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